Patient Testimony: "Lisa"
6/30/11
Michigan House Health Policy Committee Hearing
HB 4756 Genetic Counselor Licensure

Lisa was 49 years of age when she was recommended to be seen for genetic counseling and evaluation. She was seen at a local hospital's Cancer Genetics Program. She had been diagnosed with breast cancer at age 42; at the time she underwent a lumpectomy and radiation treatment. Her family history was quite strong for breast and ovarian cancer:

- Mother with breast cancer at 74
- Maternal grandmother with bilateral breast cancer
- Grandmother's sister with breast and ovarian cancer and died at 45
- Grandmother's niece with breast cancer at 68
- Grandmother's other niece with ovarian cancer at 55

Her mother's family is German and Irish, and her father's side of the family is French and English. There is no Jewish ancestry in her family.

Lisa met with a certified genetic counselor and a genetics physician and understood that her personal and family history were suspicious of a hereditary cancer syndrome, specifically the *BRCA1&2* genes. After her evaluation, she understood the potential implications of testing *BRCA+* and indicated that she would elect to have prophylactic bilateral mastectomies and a hysterectomy with her ovaries removed if she carried a mutation. Lisa's insurance, however, required her to be seen at another facility for testing where she was seen by a nurse who had been trained by the testing laboratory. *BRCA1/2* testing was ordered by this individual.

Lisa was called by this nurse to inform her that she tested *BRCA* negative, and a copy of her test results were sent to her in the mail. The patient was relieved for herself and her family members (including her two daughters – ages 21 and 23, and her 47 year-old sister), and continued her regular breast surveillance.

Four months later Lisa faxed her copy of her test results to her genetic counselor and genetics physician, since she remembered they had asked for this record at her initial genetic counseling appointment. It was noticed by her genetic counselor that she had been tested for the three common Jewish *BRCA* mutations instead of comprehensive testing (in non-Jewish individuals there are no common mutations, so you have to do the whole test, whereas in Jewish individuals, they have a specific panel they are tested for). However, Lisa was not of Jewish ancestry. The genetic counselor contacted Lisa to discuss the fact that the wrong test had been ordered and her negative result did not have much significance.

Lisa contacted the nurse who ordered her testing and requested comprehensive testing of *BRCA1* and *BRCA2*; she had to go back in for another blood draw. The nurse then called Lisa with results that she had in fact tested positive for a *BRCA2* mutation detected by the comprehensive analysis. Lisa then requested that her post-genetic testing consultation be with the Cancer Genetics Program because she wanted the most accurate information on her test results and felt much more confident in their genetic knowledge. She was shocked and dismayed that her testing had been ordered incorrectly, and that no one had caught the mistake until a genetic counselor was involved. Lisa went on to have a prophylactic bilateral mastectomies and a total abdominal hysterectomy with her ovaries removed. No cancer was detected in either of these surgeries. She has also informed her family members that they are at risk for this mutation and need to be seen for genetic counseling and testing.

Lisa knew that if she had not spoken to a genetic counselor and shared her test results with her that she never would have known she was *BRCA2* positive and at a significantly increased risk for another breast cancer and an ovarian cancer.